

National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect

Prevention Work Group Meeting August 22, 2005: Conference Call

Summary Report

Participants

Task Force Members Present: Carole Brown, EdD (Catholic University of America); Raul Caetano, MD, PhD, MPH (University of Texas School of Public Health); Deborah Cohen, PhD (New Jersey Department of Human Services); Mark Mengel, MD, MPH (Saint Louis University School of Medicine); Lisa Miller, MD (Colorado Department of Public Health and Environment); Colleen Morris, MD (University of Nevada School of Medicine); Raquelle Myers, JD (National Indian Justice Center); Melinda Ohlemiller (Saint Louis Arc); Heather Carmichael Olson, PhD (University of Washington); Jean Wright, MD (Backus Children's Hospital.);

Liaison Members Present: George Brenneman, MD, FAAP (American Academy of Pediatrics); Karla Damus, PhD (March of Dimes); Sharon Davis (The Arc); Kathleen Mitchell (National Organization on Fetal Alcohol Syndrome); Robert Sokol, MD (Wayne State University);

CDC Staff Present: José Cordero, MD, MPH (Executive Secretary); Mary Kate Weber, MPH (Designated Federal Official); Jacquelyn Bertrand, PhD; Jackie Vowell; Elizabeth Parra Dang, MPH;;

Writer/Editor: Andrea Finch (Cambridge Communications and Training Institute)

Call to Order/Welcome

Dr. José Cordero, Executive Secretary for the NTFFAS, greeted those on the call, thanking them for their time. He stressed the importance of resolving any issues pertaining to the letter to be submitted to the Department of Education regarding inclusion of fetal alcohol syndrome in the Individuals with Disabilities Education Act (IDEA).

Update on Department of Education Letter/Discussion of Content Revision/Vote

Dr. Jean Wright, Chair of the NTFFAS, verified that everyone had received a copy of the letter to the Department of Education (DOE) and had a chance to review the letter. She explained that the singular focus of this conference call was to hear people's reactions to the letter and determine whether there were any suggestions for revisions. Dr. Wright noted that the letter was addressed to Troy Justesen, who they were informed was the best person to address this letter to. Ms. Weber added that Troy Justesen is the lead person handling the public comments on the notice of proposed rulings on the IDEA regulations. His office is gathering and reviewing the public comments so it was felt that this would be the best route to proceed. Dr. Ed Sontag, who has worked with the Department of Education and is now working at NCBDDD provided advice on this issue and also reviewed the letter.

Discussion Points:

- Dr. Brown inquired whether Troy Justesen was the Director of the Office of Special Education Programs. Dr. Cordero responded that he thought Troy Justesen had been confirmed. If so, they would remove the term “Acting” and would be sure to include his correct title before the letter goes out.
- Kathleen Mitchell indicated that she had a conversation with Anne Smith, who is the DOE representative on the Interagency Coordinating Committee on FAS (ICCFAS), about possibly sending a letter. Ms. Smith indicated that they may want to send a letter to John Hager as well. Ms. Mitchell also mentioned that Troy Justesen has a PhD, so the letter should read, “Dear Dr.” Ms. Weber responded that they would make sure to make the change.
- Dr. Bertrand indicated that discussions were held with Dr. Sontag, and it was recommended that the letter be sent directly to the person compiling and reviewing the public comments.
- Ms. Mitchell suggested that it might be wise to send a copy to Anne Smith to let her know that this information has been forwarded to the Department of Education. Dr. Brown thought copying Anne Smith would be fine. Dr. Bertrand concurred, indicating that they could certainly send Ms. Smith of the letter as an FYI. She pointed out that Dr. Cordero would receive a copy of the letter, which he would put forward to CDC leadership to ensure that everyone was informed.
- With respect to the process, Dr. Cordero indicated that the letter addressed to Troy Justesen would become part of the docket of responses to the specific request for comments related to the IDEA regulations. Under Troy Justesen’s leadership, the DOE will review the entire docket and will ultimately make recommendations to the Secretary to add to the language of the regulations. It is important for the Task Force to make a compelling case pertaining to why Fetal Alcohol Syndrome should be included in the regulation, and should offer specific places within the regulation where this actually could be done.
- Dr. Brenneman inquired as to why the term “Fetal Alcohol Syndrome” was used instead of “Fetal Alcohol Spectrum Disorders?” Dr. Bertrand responded that this came about because of two issues. One, if they used “Fetal Alcohol Spectrum Disorders,” they would have had to go through and define it, which would have been a very lengthy process that distracted from the letter and the point. Secondly, the working group felt it was important to get “Fetal Alcohol Syndrome” on the radar screen. Once the condition is included in the regulations, they can then build upon it in subsequent efforts.
- Dr. Miller pointed out that FAS and specific learning disabilities, and FAS or related conditions, were mentioned on page 3. It was not clear to her whether FAS was what they wanted, or if they were asking for more than FAS. Dr. Bertrand responded that they were looking to autism to serve as the model to show how these actually get implemented in the field. Autism is included in the regulatory language but the other conditions within the autism spectrum are not. The group felt that getting FAS into the language could open the door for additional alcohol-related conditions being added in the future.
- Dr. Cohen added that this issue may have been discussed in the Post-Exposure Work Group versus the full Task Force. The list of disorders in IDEA is based on diagnoses. There was concern that if they put in “Spectrum Disorders” it would raise the issue regarding whether

this is a diagnosis, which would be rather confusing. Hence, using just “Fetal Alcohol Syndrome,” which is a diagnostic term, was simply much cleaner.

- With respect to page 3, Dr. Bertrand reiterated that they were trying to educate the DOE that there is a spectrum of conditions so that if the Task Force was to come back at some later date to address this, it would not be a complete surprise. In response to Dr. Miller’s comment regarding learning problems versus learning disabilities, she said she was willing to substitute the phrase “learning problems” in place of “learning disabilities.”
- Dr. Cordero pointed out that on page 3, in the first paragraph, CDC provided the first federal funding for intervention studies specific to children with FAS or a related condition. In this case, what CDC funded was more than FAS, so he thought this was a true statement. Dr. Bertrand suggested that in the next sentence down, they could change “inclusion of FAS and specific learning disabilities resulting from prenatal alcohol exposure” to “inclusion of FAS and learning problems resulting from prenatal alcohol exposure.”
- Dr. Sokol was concerned that they would cause a lot of problems by not including the rest of the spectrum. He stressed that FAS is no more an accepted diagnosis than FASD, and expressed concern that they may be conveying the idea to make the diagnosis of full FAS. This could result in a teenager who does not have full FAS, but who will not be diagnosed. This type of individual needs to be included. With that in mind, Dr. Sokol said he would talk about the spectrum and all of the subtleties. He would use the term “FASD” and discuss it in that respect. Dr. Brenneman concurred.
- Dr. Bertrand stressed that they were using “autism” as their model, which is not phrased as “autism spectrum disorders.” She did not think they would exclude anyone by doing this.
- Dr. Cordero thought the challenge they were going to face were people who would review this but who were not in the medical field. Someone may consult ICD-9 where they would find traumatic brain injury, hyperactivity, diabetes, epilepsy, et cetera. However, they would not find FASD. He also pointed out that many other groups would be making recommendations as well, so basically, they were trying to “get their foot in the door” to include FAS within IDEA. This would merely be the first step to moving forward.
- Dr. Sokol stressed that much of the literature has shown that behavioral effects have not been seen in full FAS. Dr. Cordero agreed, pointing out that people could argue that those were included under learning disabilities or other issues for which children could receive services. Dr. Sokol disagreed that these children would receive services, given that they do not have low IQs. Dr. Bertrand stated that IQ did not come into play with respect to learning disabilities. They are based on functional deficits.
- Dr. Caetano expressed concern with the length of the letter. Dr. Bertrand agreed, but indicated that she had made many attempts to shorten the letter. She worked through the letter point by point with the editorial staff at CDC to determine whether there was anything they could possibly omit. While she was willing to take suggestions from the group on condensing the letter, she felt that the information that was included should not be omitted.
- Dr. Brown indicated that she had worked on regulations on early intervention a number of years ago and did not think that it would be a disservice to have a longer letter. She assured the group that the letter would be taken seriously at its current length. During the meeting in June, someone suggested that maybe they should send more information to support the

scientific basis of the disabling aspects of FAS. Given that the letter is their entrée for getting information into the regulations, and because the law does require that more emphases be placed on scientific information, the long letter would probably work in their favor. Dr. Bertrand responded that they will be sending enclosures of the FAS Guidelines for Referral and Diagnosis, the updated Surgeon General's Advisory that shows that this is timely and relevant; and the Task Force article on the national agenda for FAS published in *Morbidity and Mortality Weekly Report* in 2002. The purpose of including this information was to further educate the DOE about the Task Force and about the issue.

- With respect to page 2, Dr. Carmichael Olson noted that just before the three options, the letter states, “with Option 2 deemed most appropriate.” She found this to be confusing because, in fact, all three of these changes could be made which would lead to Dr. Sokol’s issue regarding FASD, especially if Option 3 was included. Dr. Sokol agreed, suggesting that all three options should be offered. It was not clear to him why Option 2 was better than Options 1 and 3. Dr. Bertrand responded that a lengthy conversation took place with regard to that as well. Certainly, the best case scenario would be acceptance of all three options. However, they also wanted to offer the option of getting at least one concept included. All of the ongoing Task Force conversations over the years generally came back to the “Other Health Impairment” category.
- Dr. Cordero reported that they discussed these options with Dr. Sontag who understands how the Department of Education acts and thinks. The draft before this one had three options because everyone thought that was better than one or two options. However, the advice received was that it was unlikely that the Department of Education would change three parts of the regulation. With that in mind, a determination had to be made with respect to which of the options was more likely to be understood and accepted.
- Dr. Carmichael Olson stressed that the letter seemed to be suggesting that only one option should be chosen, and that the Task Force suggested Option 2. However, she thought they should make clear that if the Department of Education planned only to choose one, then Option 2 would be preferable. However, this should not appear to be multiple choice. The letter should make clear that all three should be considered.
- Ms. Mitchell suggested using the term “sections” as opposed to options. Others agreed with this suggestion and that the wording should suggest more clearly that all three sections could be chosen, but if only one was going to be, the second one was preferable. Dr. Cordero responded that they would make this very clear.
- Dr. Sokol inquired as to why it was thought that item 2 was the most likely to be accepted. Dr. Bertrand explained that it was because the majority of children included in a variety of databases who were qualified for special education were categorized under “Other Health Impairments.” Thus, the Department of Education already feels comfortable with including children of FAS in this category. Whereas, getting into Option 1 would be extremely difficult because of the definition of a child with a disability. Option 3 is somewhat looser and discrepancies have to be scored. Option 2 actually allows the greatest amount of leeway in getting a child into the “Other Health Impairment” category.
- Presuming that Dr. Justesen was interested and this moved forward, Dr. Carmichael Olson inquired as to how much additional discussion and interaction would occur between the Department of Education and CDC regarding these specific sections. Dr. Bertrand responded that there would likely be very little additional discussion/interaction. The Department of

Education would have the option to call or write to CDC with questions and they will respond to public comments. Dr. Cordero stressed that the Department of Education was expected to receive hundreds if not thousands of comments. Hence, it was most likely that there would be absolutely no response, or perhaps even any acknowledgement from the Department of Education to the Task Force that these recommendations were received. The point was that the recommendations needed to be in the docket in order to raise them as important issues. They could visit Troy Justesen and John Hager as a parallel action to the letter to urge them to consider this as something that actually needs to be done. Dr. Bertrand added that the Task Force's letter may be bundled with other letters from parents or other groups into a single response to the FAS issue.

- Dr. Davis indicated that the Arc planned to include something in its comments as well. She shared the Task Force's letter with their Executive Director and Public Policy Director. She pointed out that Paul Marchand was highly respected and would be involved in helping develop the final regulations, or commenting on them.
- Assuming that the Task Force planned to leave Option 2 as the best shot, Dr. Brown wondered if it would be possible to include some language concerning brain injury, such as, "Fetal Alcohol Syndrome and brain injury, including that which results from prenatal alcohol exposure..." Dr. Bertrand responded that where items were included really would come from people who work within the Department of Education. She thought they were taking a major risk by moving things around that way. Dr. Brown clarified that she was trying to get at the spectrum issues in the "Other Health Impairments" section, and was suggesting the addition of brain injury in that section. She was concerned that if they really were focusing only on Option 2, they were eliminating a shot at Option 3.
- Dr. Bertrand pointed out that in Option 3, the phrase was really modifying or adding to the category of brain injury. They did not include brain injury under "Other Health Impairments" and she did not believe they had the expertise to argue for including brain injury resulting from prenatal alcohol exposure as an "Other Health Impairment." The idea was to give the Department of Education all three Options, and to stress that Option 2 might be the most viable if they had to choose just one. She was not particularly worried about the spectrum because she had worked with a lot of education departments. The spectrum for children getting qualified under "autism" is not an issue.
- Dr. Damus pointed out that many children never receive the diagnosis of FAS, and if they do not, they will not be covered by this, which was why she thought that Dr. Sokol's comments were correct. There may be other disabilities associated with FASD; therefore, suggesting FAS and Option 2 was limiting. Dr. Bertrand said that by a limited interpretation of the regulations, any child with PDD, Asperger Syndrome, et cetera would not qualify, which they knew was not the way it was operationalized.
- Dr. Morris added that she thought FAS and autism were different in that regard because in practice, they used the ICD-9 code for FAS, because they are part of the spectrum. In her mind, they had a diagnosis within the spectrum. Therefore, they should qualify. Being in the trenches, in fact, they do qualify under "Other Health Impairments" in those circumstances.
- With respect to the wording in the second paragraph of the letter, Dr. Sokol inquired as to what was meant by "subtle changes in IQ" (e.g., did that mean just a couple of points?) He thought this was very strange usage and that "memory recall problems" was an equally strange phrase for a developmental abnormality. Dr. Cohen indicated that this language

came directly from the opening sentence of a CDC study. The point they were trying to make was that certainly, the IQ should not be the gold standard to use to determine whether a child with FAS received special education or not. Regarding memory, Dr. Bertrand clarified that someone could also have memory encoding or memory retrieving problems. They were trying to make the problems and deficits accessible and within the vernacular of the Department of Education. She said she could remove “recall” if that was problematic.

- Dr. Sokol said that most people in child development would not consider attention deficit to be a mental health problem. Dr. Bertrand indicated that this came out of Dr. Streissguth’s work, which was exactly where those numbers came from. Therefore, Dr. Bertrand suggested being consistent with that report.
- Dr. Cohen suggested changing “subtle changes” to “mild changes” or “moderate changes.” Others agreed.
- With respect to the last paragraph on page 2 of the letter, Dr. Damus inquired as to whether anyone really thought they were seeing an “appropriate” federal response. Dr. Bertrand responded that they were seeing a growing federal response. Dr. Cordero noted that “growing” was different from “appropriate.” Dr. Bertrand said she was willing to change the term to “growing.” She wanted the Department of Education to understand that other federal agencies recognize FAS as an important issue to address.
- Regarding the second paragraph on page 1, Dr. Carmichael Olson suggested looking at Dr. Streissguth’s data again just to ensure that they were really reporting on just children with FAS, because she thought some of those data were reporting on the full spectrum. That is, the letter reads, “. . . with over 60% if children with FAS older than 12 years . . . experiencing disrupted schooling,” which she thought was the full spectrum. Dr. Bertrand indicated that she would check the numbers.
- Dr. Sokol inquired as to whether Dr. Streissguth actually used the term “mental health problems.” Dr. Carmichael Olson verified that she does and that she includes attention deficit within that. It has to do with the secondary disabilities. Dr. Sokol felt that this was bad terminology. Dr. Bertrand said that may be, but it was the reference that the Department of Education would recognize. Dr. Carmichael Olson suggested that it could be changed to “issues.” She clarified that the reason she raised the issue regarding Dr. Streissguth’s data was because it dovetails with the fact that they give data on the full spectrum, and then just use the term FAS. She said she absolutely understood the need to be conservative in this letter, and having participated in creating the letter in the first place, it was tricky. She reiterated that they could make it clear that the Department of Education could pick all of the options. With that in mind, she suggested adding a sentence or two after the sections to clarify that growing research indicated that there was a spectrum that included FAS and related conditions. This may allow them to work later with the Department of Education to specify the terminology more broadly, as the regulations were being interpreted. She believed the data existed to suggest that there really is a spectrum. Dr. Bertrand agreed, indicating that she would review the letter to determine whether there was space to do this concisely.
- Dr. Sokol suggested that to get away from using the term “spectrum disorders,” some of the time they could use “FAS and related conditions.” Dr. Bertrand responded that this was in the letter in some places, but she would consider where else they could add this. Dr. Sokol

thought this would also take care of the statement that “40-70% with FAS or related conditions become involved with the juvenile or criminal justice systems.”

- Dr. Caetano suggested shortening the letter. He wondered if the paragraph after Option 3 was really necessary. Dr. Sokol and others like the paragraph because it included the Surgeon General and Congress. Dr. Bertrand pointed out that this was included to give legitimacy to what was going on at the federal level and to pull the Department of Education into the fold. Dr. Cordero agreed, pointing out that this was basically providing the political rationale for why this needs to be done. Given that explanation, Dr. Caetano indicated that he understood what they were attempting to do with respect to legitimacy.
- Regarding the last sentence in the first paragraph of the letter, Dr. Damus pointed out that the Task Force is not made up of just scientific and educational communities—families are represented as well. In addition, she expressed concern that they seemed to be blaming women by the statement in the second paragraph on page three reading, “We, as members of the Task Force, are committed to ensuring that all women of childbearing age understand that FAS is entirely preventable.”
- Dr. Bertrand responded that she thought families were included in the sentence, but indicated that they could certainly make this explicit. Regarding the potential perception of blaming women, Dr. Sokol suggested leaving out the entire sentence and let the paragraph begin with, “We, as members of the Task Force, are committed to ensuring that all children affected receive educational and social services,” given that this was what this letter was about. Others agreed with the suggested deletion. Alternatively, Dr. Damus suggested the statement, “We, the members of the Task Force are committed to preventing FAS and to ensuring that all children who are affected . . .”
- Dr. Carmichael Olson added that if they were going to say this, this may also be the place to say, “spectrum disorders or related conditions” so that they once again embrace the fact that the whole spectrum is what they are focused on.
- Ms. Weber indicated that the deadline for submission of public comments on IDEA would be September 6th, so as soon as these changes were made, the letter will be sent forward.
- Ms. Ohlemiller inquired as to whether they resolved the issue of the term “subtle changes in IQ” Dr. Bertrand responded that she thought they did by changing “subtle” to “mild” and eliminating “recall.” She said she would double check the numbers to ensure that they matched, and in the parenthetical statement about ADHD, she would change “being diagnosed” to “issues with.”
- With respect to reporting on the secondary disabilities data, Dr. Carmichael Olson recommended reporting the full spectrum statistics, perhaps with one alarming statistic that is focused only on FAS, which again would make the point that it is the full spectrum about which they are concerned and that FAS is a problem as well. Ms. Ohlemiller responded that this was what they had done because the middle of the paragraph says “children with FAS or related conditions often exhibit a wide range . . .,” but then goes on to give some specific steps, which she thought were about FASD, not FAS.
- Dr. Bertrand stressed that she would review the statistics used. They were trying to strike a balance, which she thought the letter did from a scientific perspective. If the numbers of children who needed services were too high, action might not be taken because of the

challenges to provide services. So, there is a balance to be made. Certainly, the burden of providing services will be taken into consideration. Dr. Bertrand reminded everyone that the major point of the letter was to “get their foot in the door.”

- Dr. Wright inquired as to whether they needed to have the vote in writing, or whether they could simply take it by phone. Dr. Bertrand responded that they could take the vote by phone.
- Dr. Cohen put forth a motion that the letter with the amendments be approved and sent to the Department of Education. Dr. Sokol seconded the motion. Ms. Weber indicated that they needed to take a vote on this, directing each member to state “yeah” or “nay” in order to document the vote for the minutes.

The call for a vote was made:

Yes - 10 Jean Wright, Carole Brown, Raul Caetano, Deborah Cohen, Mark Mengel, Lisa Miller, Colleen Morris, Raquelle Myers, Melinda Ohlemiller, Heather Carmichael Olson

No - 0

Absent: Faye Calhoun, James Berner

While liaison representatives are not voting members, those present endorsed the letter (Robert Sokol, Karla Damus, Sharon Davis, George Brenneman). Absent from the call: George Hacker, Kathleen Mitchell (dropped off call prior to vote)

With a vote of 10-0, the letter with amendments was approved.

- Dr. Damus indicated that the letter had been reviewed by the Medical Director and others at the March of Dimes. They want the Office of Governmental Affairs to do what they can to support this effort. Unfortunately, both Marina Weiss and Bill Merrill were on vacation until the following week. However, Dr. Damus requested a copy of the final letter. Dr. Weber indicated that they would make the changes and the letter would then be sent forward to everyone. Dr. Bertrand indicated that as much as those two letters could be consistent, she thought it would help the Department of Education and reduce confusion on their part.
- Dr. Wright thanked Dr. Cohen for initiating this letter and everyone else for moving it forward, because it had not been a simple task to complete. Dr. Cordero asked everyone to be prepared for the work that needs to happen afterward behind the scenes.

Public Comments

Ms. Weber called for public comments; however, no public comments were offered. There was a motion to adjourn, Dr. Wright so moved, Dr. Damus seconded, and the motion carried. Dr. Cordero thanked those present and the call was officially adjourned.

I hereby confirm that these minutes are accurate to the best of my knowledge.

Minutes approved on 10/17/2005
by Jean A. Wright, MD, MPH
Chair, National Task Force on FAS/FAE